National Sickle Pain Group - Acute Sickle Pain Subgroup

Action Plans to Providers to improve care for sickle cell patients presenting with acute sickle pain

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In the recent All Parliamentary Part Group on Sickle Cell and Thalassemia's report 'No-one's listening' published in November 2021[1], it is recommended that 'all NHS Trusts develop an action plan setting out how they will ensure compliance with the NICE clinical guideline[2] around the delivery of pain relief within 30 minutes for sickle cell patients'. The Acute Sickle Pain Subgroup propose the following action plans to be adopted by NHS Trusts providing care to patients presenting with acute sickle pain.

The acute pain group recognises it is difficult to standardise pain management. There are also a variety of challenges impacting on optimal care provision and it is understood that different solutions may apply to different services. However, it is important to emphasise that the recommendations and action plans are not intended to be a 'one shoe fits all' mandate. The document aims to propose areas /guides that Trusts could use to guide conversations and actions to implement care improvement initiatives.

Key Recommendations NHS Trust

- **Develop multidisciplinary teams for acute sickle pain involving Emergency Department Specialists, Acute /General medicine specialists, haematologists, ITU specialists and pain /palliative care team representatives.** The aim of the teams would be to promote collaboration, identification of care barriers and promote action to remove them.
- **Develop education plans for staff providing care to sickle cell patients receive education around sickle cell acute pain care and positive, caring attitudes.** The implementation and continuation of the educational initiatives need to be owned by each relevant service (for example Emergency Departments or Acute Medical Teams) and collaboratively delivered by experienced practitioners.
- **Develop patient sickle cell pain management protocols, with the involvement of patient representatives.** In case of complex pain needs, the protocols would ideally be individualised, however in the absence of these, there can also be a trust-agreed generic pain protocol used.
- **The Emergency Department and Acute Medical Teams should explore alternative routes for analgesia administration in case intravenous (iv) access is difficult (such as subcutaneous, transmucosal or intranasal) and incorporate these into patient pain management protocols.**
    - Following initial analgesic dose, repeated doses of analgesia and close monitoring of patients for pain severity and opioid toxicity, in accordance with NICE guidance, should also be ensured.
    - Trusts should promote PCA setup at the Emergency Department if/as needed, to ensure seamless pain relief through inpatient stay.
    - Gradual withdrawal of analgesia is advised, to reduce the need for large doses of opioids prescribed in the community following discharge.
- **For complex pain or suboptimal pain response to analgesia according to patient protocol, Trusts need to develop pathways with expert pain team involvement to guide pain relief.** We propose a step-by-step approach, depending on complexity of pain relief requirement, with involvement of pain/palliative care and anaesthetic teams as required.
- **Explore Day Unit setting development for treating patients presenting with acute sickle pain, where possible, to improve and optimise management.**

Areas of focus and Action Plans recommendations

The acute pain subgroup has identified areas of care and services where care provision improvement needs to be focused and prioritised.

1. **Basics of Care**

All staff caring for patients with sickle cell disease, including Acute Medicine and Emergency Department staff, should take into account the basics of care for sickle cell disease patients:

- Ensure patients are kept warm (maintain warm room temperature, offer blankets especially at night when the temperature often drops).
- Ensure patients are offered oxygen via nasal cannula or mask, as needed.
- Ensure good oral hydration or intravenous hydration if oral intake is insufficient
- Ensure patients are offered food.
- Ensure medication is being administered regularly.

2. **Joined-Up Care:**

Teams involved in care provision to sickle patients presenting with acute pain need to collaborate to determine/identify service and/or trust-specific challenges to optimal care provision. Meetings should include all relevant teams (including but not limited to Haematologists, Acute/General Medicine Specialists, and Emergency Medicine Specialists). The goal it to identify barriers to optimal care specific to each provider and to promote joint action to remove them. It is recommended that a multidisciplinary team is created involving key specialties that are involved in acute sickle pain care provision, such as Emergency Medicine Specialists, Acute/General Medicine Specialists, haematologists, ITU specialists and pain/palliative care teams.

3. **Education and staff attitudes:**

Even in the presence of optimal protocols and pathways, optimal care provision will be significantly compromised if staff involved in care provision to sickle cell patients are unaware or don't recognise the importance of prioritising timely pain relief and offering compassionate care to sickle cell patients. NHS Trusts need to implement education plans where staff receive education around sickle cell acute pain care and positive, caring attitudes. Incorporating education into mandatory training will help ensure that all key staff receives training. Educational initiatives may be developed with the collaboration of all the relevant services and delivered by experienced practitioners in sickle cell disease, but the implementation and continuation of education needs to be owned by each relevant service (for example Emergency Departments or Acute Medical Units).

4. **Patient management protocol availability**

NHS Trusts need to develop patient pain management protocols, with involvement and agreement of patients. In case of complex pain needs, the protocols would ideally be individualised. In the absence of an individualised pain protocol, there can be a trust-agreed generic pain protocol that can be used. These need to be made accessible and available to patients and to relevant services that the patients may use for acute pain care. NHS Trusts are encouraged to explore uploading protocols in appropriate accessible platforms (for example the National Haemoglobinopathy Registry or Coordinate My Care) for visibility to multiple key stakeholders (such as other Acute Trusts or the London Ambulance Service).

5. **Administration of analgesia**

One of the causes for delays in pain relief is challenges with iv access in many patients' cases. NHS Trusts need to promote education around use of alternative routes of analgesia administration and emphasise that lack if intravenous (iv) access should not hinder timely pain relief. The Emergency Department/Acute Medical teams should explore alternative routes for analgesia administration in case iv access is difficult (such as transmucosal, intranasal or subcutaneous) and incorporate these into patient pain management protocols. The National Sickle Pain Group is promoting research into this field but in anticipation of sickle acute pain-specific research outcomes. In addition, lessons should be learnt and examples followed from existing research into cancer pain relief.

Another area for improvement is follow-up doses of analgesia after initial dose and Patient Controlled Analgesia (PCA) setup in the Emergency Department. Any delays in follow-up analgesia doses result in pain recurrence and suboptimal care experience. NHS Trusts should ensure there is close monitoring of patients for pain severity and signs and symptoms of opioid toxicity, to ensure patient safety.

Following pain control and improvement, gradual withdrawal of analgesia is advised, to reduce the need for prescription of large doses of opioid medication in the community and outpatient setting.

Trusts should promote PCA setup at the Emergency Department if/as needed, to ensure seamless pain relief through inpatient stay.

6. Complex Pain Needs

For situations where patients have complex pain needs or pain does not respond to analgesia according to their protocol, NHS Trusts need to develop pathways with expert team involvement to guide pain relief. We propose that at a first step, patients presenting with acute sickle pain can be managed in accordance with their pain protocol/Trust protocols and national guidance by the Acute Medical Team or Haematology Team. Should pain relief be inadequate, as a second step, specialist team input is necessary to guide management decisions (acute/specialist pain team or palliative care team). If pain relief is ineffective in this setting, then we advise, as a third step, that Anaesthetic specialists are involved and care provided in an enhanced setting (HDU/ICU) with consideration for alternative pain-relief agents.

7. Organisation of Care

The acute pain subgroup recognises challenges facing acute providers regarding Emergency Department demand and capacity. NHS Trusts are advised and encouraged to explore development of Day Unit settings, where possible, to improve and optimise management for acute sickle painful episodes. The National Sickle Pain Group audit questionnaire data revealed that time to first analgesia dose and overall patient experience were improved in dedicated Day Unit settings in comparison to Emergency Department attendance[3]. Additionally, there are multiple references in the literature of the benefits of establishing day units for the management of uncomplicated acute sickle painful episodes[4, 5, 6].

8. Paediatric care

The above recommendations apply for paediatric services as well as adult services caring for sickle patients presenting with acute pain. However, we recognise that paediatric care may be organised and delivered differently in NHS Trusts, and paediatric wards and services might have distinct care pathways for acute pain and emergency department presentations. Therefore there may be a need for earlier consideration of anaesthetic involvement and alternative analgesia routes/agents. The fundamental principles of care delivery detailed in this document are applicable to both adult and paediatric settings.

References

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